

COMMENTARY

Transition-Risky Business for Our Sickest Kids

I used to begin a discussion of **transition** of chronically ill patients into adult life with a comment on how the topic of transition appeared to induce a blank look in many of the medical students, residents, and attending physicians in the audience, a blank look that seemed to mean “What does that nebbish word mean anyway?” Then once they understood what transition means, some would start falling off one by one into twilight of boredom and somnolence. Now I don’t worry about the spellbinding effects of the word transition as I can genuinely mix in some angst of too many painful, difficult transition situations that keeps many in the audience alert and interested. But I believe that some in the audience, particularly more acute care physicians (e.g., surgeons, neonatologists, emergency room and ICU physicians), may not be sharing their inner-most thoughts such as “Just transition them at 18 and forget about it, already.”

Why not, indeed? Is transition often difficult for us because we are too nice, too “touchy-feely” as pediatricians, because we are physicians who care for their kids way too much and hate to let them go? I believe that there is a core of truth to these descriptions but it can be overstated. I believe our trouble letting go is more due to the nature of the care of chronically-ill children, teens, and young adults and our efforts to help them become successful, well-adapted, and healthy adults. Do we have concerns trusting some of our internal medicine colleagues with these 18-25 year-olds patients, when some (but not all) of these patients are immature, poorly compliant, have a poor social support system, and are still much more an adolescent than an adult? Do we think most internist rheumatologists can’t do as good a job as we can with chronically-ill teens and young adults? I believe that that many pediatric rheumatologists may feel this way to some extent, but this too may be overstated. But these beliefs are usually in the background during transition discussions and need to be acknowledged up front.

So it's so much more than too nice pediatricians and lack of trust of our internal medicine colleagues. It's because for our sickest patients, particularly the lupus and MCTD kids, the passing of the baton to the internists poses some risks. If the teen and family are not ready for the challenges of adult life, major social and medical problems may arise. During this settling-in period of 1 year or so when the rheumatologist really gets to know the transitioned patient, I believe the patient is at greater risk for medical complications and events than before the change or after the first year of transition. Despite our best communication of letters, phone calls, e-mails, medical records, flow sheets, and medical history from the patient and parent, it takes awhile for the internist rheumatologist to really know the patient as we know her/him. In my experience, medical crises may be more likely during this 6-12 month transition as the new patient-doctor relationship develops. After 5-20 years of disease, the teens and young adults may be just developing major organ involvement and complications of systemic disease and are more at risk than they were in the early years of their illness. The need for transition can come at an inopportune time.

If the pediatrician firmly transitions without giving the patient encouragement to keep in touch and the patient doesn't take to the new rheumatologist, the patient may simply drop out and fall between the cracks for awhile, not seeking medical care from anyone. It's crucial for the pediatric rheumatologist who is saying goodbye to make it clear that she/he is open to an occasional phone call or visit in the first year of transition-not for prescriptions or lab tests but for advice and support. So from my perspective, the "just see him/her one more time and I'll take over" approach the internist rheumatologist may suggest is often inappropriate. On the other hand, though we may not want to admit it, the new viewpoint of the rheumatologist may provide added insight, experience, and welcome changes in treatment. But I fear the former result in some of our really difficult and "patient-fatigue" patients: e.g., inner city lupus patients with severe renal disease or on dialysis, severe chronic continuous dermatomyositis teens, difficult scleroderma patients, and worst-case scenario JIA kids.

What can we do to help these patients have their soft landing? First, we as pediatric rheumatologists must try to prepare our teens and young adults to make the transition jump. It starts several years before the actual transition and involves encouraging greater independence, discussion of education and vocation, recognition of school problems common to this population, and bringing up sexuality. It means looking for a period of stability and compliance for transition and avoiding transition at the time of an emergent admission to an adult medical floor. Some of these important guidelines are delineated well in the below list and in the transition checklist in Figure 1 (modified from guidelines of Children's Hospital of Philadelphia with permission from Patty Rettig, RN)

These strategies have a number of basic, core principles:

- 1) Transition is a process, not a date.
- 2) Consider maturational level rather than chronological age.
- 3) Transfer should occur when the disease is stable and well controlled and not during crisis or medication change.
- 4) Transition should be delayed if there are transitional and social interventions (financial, insurance, life events, community referrals) pending until there is a reasonable resolution.
- 5) The teen should be prepared for the transition-the rheumatology team should encourage independence, not dependence, and teach self-care skills including medications and reporting their disease status.
- 6) The rheumatology team should emphasize the vital link between education and vocation and the crucial importance of realistic vocation aspirations and plans.
- 7) Despite the above obstacles to transition, for many patients, the pediatric rheumatologist may have to initiate the final stage of transition and push the patient and family to "make the move". Many patients and families are reluctant to change doctors.
- 8) On the other hand, transition should not be communicated as an iron curtain coming down lest the patient and family feel abandoned and if the

transition is unsuccessful, the patient and family feel reluctant to contact the pediatric rheumatologist for advice or temporary help.

What other strategies can we use? These strategies may vary from one medical center/medical school to another. It may be helpful for a pediatric rheumatologist to locate one or more internal medicine rheumatologists in their medical system that he/she works well with, who are comfortable with the guidelines for transition, and are excellent communicators with young people. These colleagues are very valuable and to be sought after and cultivated. Medicine-Pediatric trained colleagues can particularly bridge the pediatric and medicine worlds and provide this resource. It's useful to set up a transition clinic or protocol that facilitates the process for the chronic disease teens in your center. It may be useful to discuss transition in faculty and section head meetings and seek consensus and a uniform approach in a pediatric department.

What other issues of transition may come up regularly? At some medical centers where pediatric and internal medicine centers are close by and allied politically, inpatient admissions for chronically-ill preteens, adolescents, and young adults 12-25 years old on adult floors can be a problem. This may not be as big a problem at freestanding children's hospitals which are not close to allied adult hospitals. If the pediatric beds are full, larger and/or older teens may be admitted to the adult medical inpatient unit of the same hospital or transferred to adult medical floors in sister hospitals. The criteria whether it's acceptable to transfer when the pediatric hospital is full from the pediatric emergency room or ICU to an adult hospital unit can vary, but may be as simple as over 12 years old and more than 40 kilograms. Due to the communication gap between the medical and pediatric system, the pediatric rheumatologist may be notified after the fact that her/his patient is now hospitalized elsewhere or may hear from the teen's parent. It is understandable that an infant is given precedence for a bed over a teen because the teen can be hospitalized on the adult unit and an infant cannot. Yet the care of the adolescent must also be optimized and given priority.

Certain difficulties may arise from these admissions on an adult unit. Medicine and pediatric medical systems do not always interface well. The

cultures and philosophies can be quite different. It's not unusual for the pediatricians not to be called by the medicine resident/attending team and the team to consult adult specialists, including rheumatologists, as both medicine and pediatrics can lay claim to the ability to care for adolescents. Continuity may be lost. Often the patient may not be transferred back to the pediatric unit when a bed is available.

The solution may lie in setting up a system of excellent communication between the two pediatric and medical systems. Pediatricians should be alerted when their long-term patient is on a medical floor. The internal medicine team and pediatric subspecialist can then work together for the best interests of the patient during the admission. It is important that the pediatricians ask their internal medicine colleagues to yield to the pediatrician's care until transition is accomplished under optimal circumstances. In the US, medicine-pediatric residents and staff can help facilitate this process. Once our patients are over 21 years old and needs admission to the hospital, it is prudent to involve our adult rheumatology colleagues and work through them.

Patience White, Susan McDonagh, Patty Rettig, and others have been leaders in studying the best ways to transition our patients. We have a lot of opinion, including this commentary, about transition. We need more evidence-based medicine about how to properly transition our special patients. A starting point may be establishing a transition clinic in each major pediatric rheumatology staffed by a pediatric rheumatologist and an adult rheumatologist and multidisciplinary staff. The clinics might care for teens between 18 and 21 years and provide the bridge between the two systems as well as provide an environment for the needed research in transition.

Transition may be a nebulous topic to some, but to those of us caring for a large number of chronically ill adolescents, it is a critical issue. It becomes more problematic the longer you practice pediatric rheumatology in the same location. Your 2 year old with severe systemic JIA becomes a transition challenge 15-20 years later. Pediatricians are unique in medicine in the obligation we have to surrender our patients to the adult health care system at some point in time. We

owe our patients with rheumatic disease and other chronic illnesses the best transition possible, especially for those patients with severe, difficult disease.

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REFERENCES FOR THOSE INTERESTED IN MORE READING:

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Rheumatology Transition Checklist for Teenagers

Name _____

Date _____ Remember to bring list to each appointment!

This checklist is to help you prepare for and transition to adult care. You can *achieve independence* in matters of your health and future!

You Will Track Yourself:	Plan to start	Needs Practice	Does independently	Comments and Contacts
Discusses chronic condition and impact				
Discusses concern/issues about transfer of care				
Participates in support group, camp, teen programs Interacts with teen, young adult role models				
Understands differences between pediatric and adult care, verbalizes expectations				
Prepares questions and speaks up at medical visit				
Participates in "Teen Visits"				
Takes medications/does exercises & treatment correctly				
Keeps "diary" information – medication & doses; doctor & team names, phone numbers; BP, wt, relevant info				
Calls for prescription refills, lab results, etc. and schedules appointments				
Calls to report flare, change in illness, new symptoms, questions ,concerns,				
Knows insurance. Has plans for continuous medical coverage after transfer				
Continues primary care visits. Has plans for primary care after transfer				
Obtains sexual/reproductive health information and appointments				
Independent with dressing, bathing, chores. Uses devises for "ADLs" if needed				
Discusses how drugs, alcohol,				

cigarettes affect illness and medication toxicities				
Contacts agencies: Vocational Rehab, driving, college office for students with disabilities, financial aid, etc.				
Discusses and plans for time to transfer care				
Chooses adult physician – makes appointment				
Adult Rheumatologist: _____ Address: _____ Phone Number: _____ First Appointment Date: _____				
<hr/> <p><i>Congratulations! You are ready!</i> <i>Developed by Patricia A. Rettig,</i> <i>MSN, RN, CRNP, The Children’s Hospital of Philadelphia revised 10/03</i></p>				